

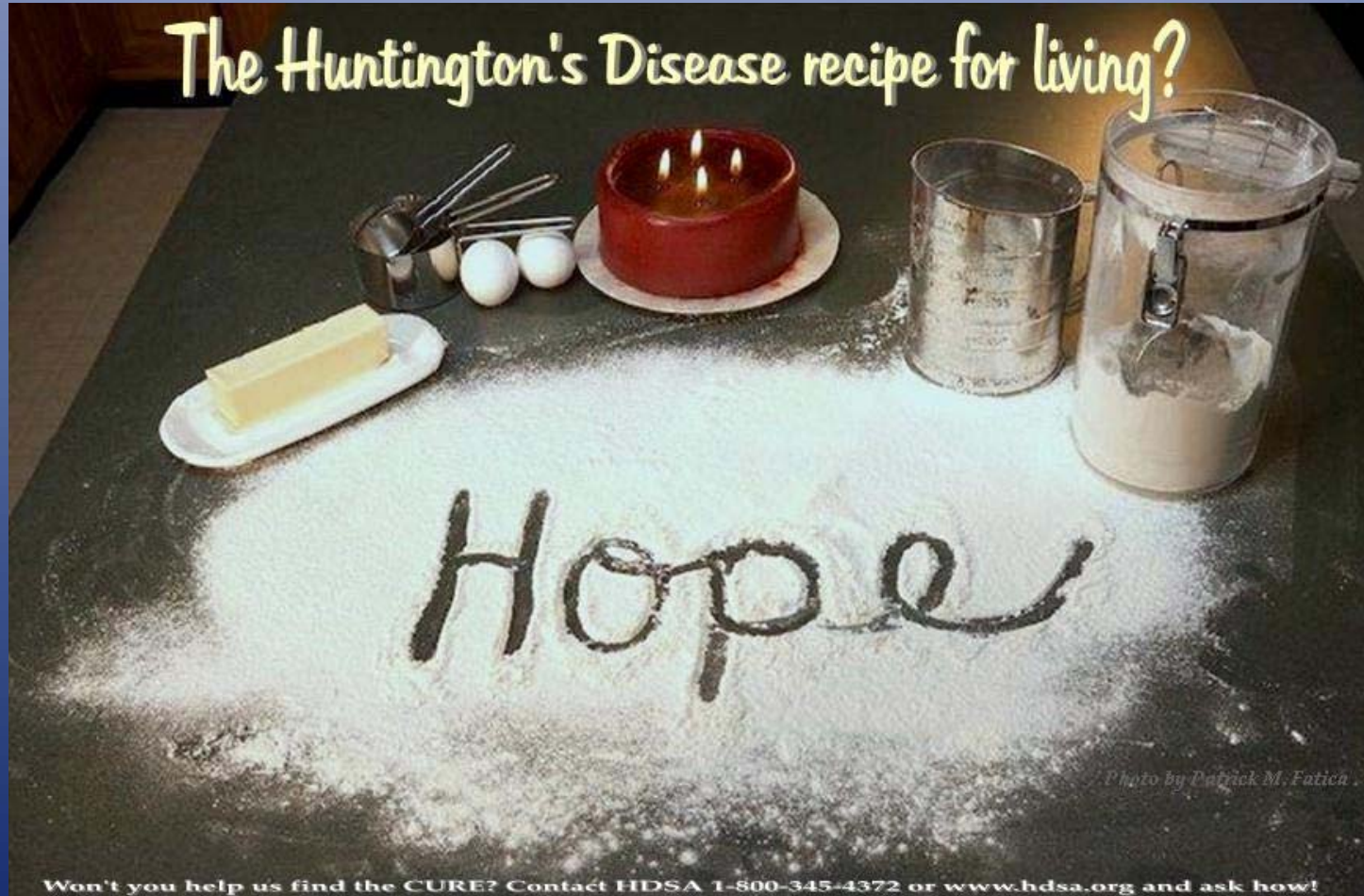
# Taking the Clinical Trial Message Home

Why and How: For the Lay  
Community

# Why take the Message Home?

- To give hope; with hope comes the energy to participate.
- To raise awareness about clinical trials.
- To communicate the critical need for participation.

# The Most Important Ingredient: But No Cake without Clinical Trials



# We know its a good thing, but how to teach?

- Communicate the excitement.
- Learn more about the drugs being tested. You don't have to be a scientist to get this message across.
- Show the need: Large numbers of people, and shorter recruitment times
- Teach the basics of the process.

# Communicate the Excitement

No one will be interested in a clinical trial if we don't show it is worth the effort.

List the trials and drugs. It is remarkable how many.

Learn about trials and drugs from HDSA, HD Lighthouse, HDDW and government sites.

Tell them a little about each one.

# Show the Need

Nearly 800 needed now:

- 2CARE: 600 participants at 43 study locations
- PRECREST: 80 in Boston.
- Memantine: 40 Kansas, John Hopkins
- Citalopram: 36 in Iowa

## And Within the Next Year . .

- Nearly another 1000:
- CREST: 650
- Dimebon: 3 or 400 for phase III
- ACR-16: about 100
- PREQUEST 80

## and . . . That's just the Beginning

- CHDI anticipates their first trials of several potential drugs within next few years (2-5).
- With more to follow.

### Bottom Line:

- There will be long-term ongoing need for participants.
- Your sustained effort will be needed.



## Not just Numbers . . Pace of Recruitment

- Minocycline: (118) 12 centers, almost 2 years
- Dimebon : (90) 15 centers, 10 months.
- Memantine (60), 3 centers, still recruiting after several years.
- Citalopram: (36) 1 center, still recruiting after several years.

# Community is Essential

The Message is not getting out far enough or quickly enough through usual channels.

That's where you come in . . . We need **every** willing hand, lay and professional at all points of contact.

Support groups a good place to begin.

# Why Emphasize the Support Group ?

- Most frequent community outreach.
- “Hands on” learning.
- Trusted supportive environment.
- Extended family reach.

# More Reasons to Add the Lay Community Input

- Fewer restrictions: Not constrained by IRB regulations, or organizational liabilities.
- History of success in aiding recruitment and retention (Breast Cancer best example).
- The more hands working, the more we can accomplish: within chapter support groups, or our own

# Why teach the basics?

- Understanding the process can lessen fear of participation.
- It is a starting point for learning how to become self-informed.
- It increases interest and empowers the whole community.

# What are the Basics?

## My Discussion Points

- For Background: Pace and description of drug development. Introduction of CHDI.
- Tally of drugs already in trial, drugs planned for trial; drugs far along pipeline potentially near to trials.
- Mechanics of clinical studies and trials:  
Using examples of real HD trials, discuss criteria, informed consent, placebo, phases, safety, risk, possible personal issues.

# It works in the Northwest!

Northwest Project shows that the community:

- wants more information.
- is interested in clinical trial participation.
- Has relatively little basic knowledge, but learns quickly.
- Can negotiate as a group.
- Will enroll.